

# HEALTH MATTERS



HEALTH CONSUMERS'  
COUNCIL  
YOUR VOICE ON HEALTH

Health Consumers' Council (WA) Inc Magazine

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## MESSAGE TO MEMBERS

We would like to introduce our new Board Executive, stepping into the Chairperson position is Michelle Atkinson - de Garis. Our Deputy Chairperson is Cheryl Holland, with Tom Benson as Treasurer and Tony Addiscott retaining the position of Secretary. A special mention goes to our new Board Members Michele Kosky, Ruth Sims, Suresh Rajan and Catherine Lusignan - Hewber.

### Lucy Carter

Health Matters Editor

## HCC BOARD OF MANAGEMENT

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Dr Martin Whitely	Acting Executive Director
Chrissy Ryan	Advocate
Carly Parry	Advocate
Maxine Drake	Advocate
Dr Ann Jones	Policy Research Officer
Laura Elkin	Aboriginal Advocacy Manager
Leah Cooper	Aboriginal Advocacy Officer
Louise Ford	Consumer Participation Coordinator
Lucy Carter	Operations Manager
Eileen McRory	Administration Assistant

**Cover: Board members with guest speaker Fiona Stanley at the HCC AGM. From left to right Ruth Sims, Fiona Stanley, Tony Addiscott, Catherine Lusignan - Hewber, Rasa Subramaniam, Tricia Walters, Suresh Rajan, Michelle Atkinson De-Garis and Cheryl Holland. (Article page 16)**

# Forward



Dear Members and Supporters,

It has been a busy time at the Health Consumers' Council with significant staff changes. Since the resignation of Frank Prokop in early July I have been Acting Executive Director. On behalf of all staff I thank Frank for the principled and passionate service he gave the HCC during his time leading our committed and capable team.

To help fill the void in my Senior Advocate's role, two talented individuals have accepted short term part-time contracts. With sixteen years prior service at the HCC Maxine Drake needs no introduction. It is fantastic to have her 'institutional knowledge' available to all staff. Our second 'temp', Dr Ann Jones, is also a very impressive community advocate. Ann, a former academic and electoral officer, is working primarily as a researcher.

Special thanks need to go to Laura Elkin our Aboriginal Advocacy Manager. She has shouldered sole responsibility for delivering the Aboriginal Advocacy Program throughout the last year. Laura has done a great job, however she is overjoyed to at last have a second Aboriginal Advocate, Leah Cooper, to share the load. Leah has already impressed other staff with her infectious energy and passion.

One of the exciting challenges for the HCC in the coming year is to grab opportunities presented by the *National Safety and Quality Health Service Standards – Standard Two* which requires health services to place greater emphasis on consumer feedback and input. This commitment to increased consumer engagement was endorsed by all Australian Health Ministers in 2011. *Standard Two* has the potential to change the way health services are planned and run.

As a result the demand for appropriately skilled consumer representatives is increasing rapidly. In addition, the role of 'Consumer Representative' has become more onerous, creating the need for comprehensive training and support. Preliminary discussions have begun with other training providers to ensure that the HCC remains at the forefront of Health Consumer Representative training in WA.

Another change facing the HCC is the shift to 'outcomes based funding' from the WA Health Department which kicks in for us in July 2015. The HCC welcomes this innovation as it gives us the opportunity to demonstrate how we improve the lives of individual consumers and drive systemic change. The shift to a five year funding cycle is also very welcome as it will enable us to plan ahead with greater certainty. The coming months promise to be very busy and productive. On behalf of all the staff at the HCC thank you for your continuing support.

A handwritten signature in black ink, appearing to read 'Martin Whitely', written in a cursive style.

**Dr Martin Whitely**

**Acting Executive Director  
Health Consumers' Council**

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# There are limits to how far we can extend life

**Frank Smith** | Health Consumer



Hendrikje van Andel-Schipper

For at least a century life expectancy has been extended, firstly by curing infections and improvements in hygiene and more recently by steady improvements in treatment of non-infectious diseases.

“Life expectancy in Australia is increasing at the rate of one or two years per decade,” said Leon Flicker Professor of Geriatric Medicine at UWA. “In 1970 hardly anyone passed their 85<sup>th</sup> birthday. Now five percent of the population are 85 or older. In 2050, life expectancy at birth of men will be 93 and for women 95.”

But can we go on increasing our life span indefinitely? Research in the Netherlands suggests we cannot. *New Scientist* reported that analysis of blood from one of the world's oldest and healthiest women has given clues to why this is so.

Hendrikje van Andel-Schipper was at one point the oldest woman in the world. She was also remarkable for her health, with no sign of mental decline, and a disease-free blood circulatory system. When she died in 2005, aged 115, she bequeathed her body to science, with the support of her living relatives that any outcomes of scientific analysis – as well as her name – be made public.

Dr Henne Holstege of the VU University Medical Centre in Amsterdam, the Netherlands and her team have studied samples of her blood and other tissues. "To our great surprise we found that, at the time of her death, the peripheral blood was derived from only two active hematopoietic (blood forming) stem cells which were related to each other."

In contrast most adults have around 1,300 simultaneously active stem cells. This suggests most of the blood stem cells she started life with had already burned out and died. Stem cells in our bone marrow are constantly dividing to create new blood cells, but the process of cell division introduces errors, and the dividing cells can acquire genetic mutations.

The team found that the length of the telomeres - protective repetitive sequences at the ends of chromosomes – of white blood cells were 17 times shorter than those in the brain, which rarely divide and so retain the same number of telomeres as at birth. Dr. Holstege speculates that most blood-forming stem cells may have died from 'stem cell exhaustion,' reaching the upper limit of stem cell divisions.

The findings were published in the journal *Genome Research*.



# Social support benefits health

**Rachelle Fernie** | South Coastal Women's Health Services

Social support is one of most important factors in the physical health and mental well-being of everyone from children through to older adults. The absence of social support can often lead to an inability to cope with life stresses and the deterioration of physical and mental health. Support groups or self-help groups are a major factor in preventing symptoms such as depression and anxiety from developing.

South Coastal Women's Health Services provide a range of services within a social model of health, focused on promoting good physical and mental health for women and their families, including a variety of educational and therapeutic support groups held throughout the year.

These groups include Perinatal Mental Health Mothers Groups that are facilitated by trained counsellors, Family Violence support groups, and Finding Your Inner Balance relaxation and meditation groups, as well as visiting services with groups facilitated by the Sexual Assault Resource Centre and the Cancer Council, amongst others.

Self-help and support groups can also be at the forefront of preventing social isolation, providing friendship and opportunities to remain active for people who would otherwise struggle to stay socially connected, such as the elderly or disabled.

South Coastal Women's Health Services is the home of the Rockingham Outrageously Ageing Group, offering women over the age of 50 the opportunity to build friendships and enjoy outings and guest speakers on a range of topics that interest them.

Girls Against Limitations in Society is also supported by South Coastal Women's Health Services, and is a group run by women with disabilities, for women with disabilities to provide each other with support and information on living with disabilities.

For information on groups offered at South Coastal Women's Health Services, or if you would like to find out how you can start your own support group, please contact **9550 0900**.

# Licensing and subsidising pharmaceuticals in Australia - Reforms needed to deliver transparency, safety and value for money

**Dr Martin Whitely** Acting Executive Director | Health Consumers' Council

This article is a summary of a September 2014 HCC submission to the Senate Select Committee on Health. A complete referenced copy of the submission is available at [http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Health/Health/Submissions](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Health/Health/Submissions) Submission 46.

Most pharmaceutical products used by Australian consumers provide life improving and in some cases life saving benefits. However Australia's secretive, industry friendly, pharmaceutical licencing and subsidisation system causes consumers to pay far too much - both at the pharmacist and in taxes - for medications which on occasions are unsafe or ineffective.



Unlike New Zealand, our system of purchasing and pricing taxpayer subsidised drugs, the Pharmaceutical Benefit Scheme (PBS), has not encouraged price competition. As a result the wholesale price of identical drugs are 'more than six times higher' in Australia than New Zealand.<sup>1</sup>

Of even greater concern, the operations of our safety regulator, the Therapeutic Goods Administration (TGA), is far from transparent and effective. When licensing drugs for marketing the TGA relies on research funded and controlled by pharmaceutical companies. Too often pharmaceutical companies 'cherry pick' favourable evidence, and hide or 'spin' unfavourable evidence to support their commercial interests. Sometimes, as was the case for Vioxx and Pradaxa, patients pay with their lives.<sup>2,3</sup>

The TGA's post-market monitoring of drugs is equally problematic. Voluntary reporting, inadequate disclosure, and a lack of systematic analysis, of adverse events, results in an overly optimistic perception of the safety and efficacy of many drugs. Furthermore, privacy provisions in the *Health Act (1953)* effectively exempt dealings between pharmaceutical companies and Commonwealth Government agencies from Freedom of Information requirements. Reform is needed to PBS and TGA processes to

ensure their transparency, end the rip off and guarantee the safety and efficacy of drugs used by Australian consumers.

## Safety and Informed Consent Reforms

The Australian Government should require public disclosure of safety and efficacy data of all pharmaceuticals approved for market and facilitate informed consent for Australian pharmaceutical consumers by improving public disclosure of adverse event risks.

This could be achieved by:

1. Reforming Commonwealth Freedom of Information legislation to end the entitlement of corporations to rely on privacy provisions originally intended to protect the health records of individuals.
2. Require full public disclosure of all safety and efficacy data for medications approved for market in Australia.
3. Prevent cherry picking of favourable results by requiring pre-registration of all new research that may be later used to support the licencing and PBS subsidisation of medications.
4. Strengthening Consumer Medicine Information (CMI) requirements so that:
  - Every warning currently included in information to prescribers is also on the CMI.
  - It is mandatory to include a CMI inside medication packaging.
  - Putting a brief summary of the most serious (boxed) warnings on the outside packaging of drugs so consumers are aware of very significant risks. (Currently boxed warnings are often only highlighted on information made available to prescribers and are not seen by consumers.)
5. Make adverse drug event reporting to the TGA for a specified range of serious reactions (suicidal ideation, strokes, psychosis etc.) mandatory and regularly publish full de-identified details on the TGA website.
6. Require full public disclosure of pharmaceutical industry funding sources for clinicians, researchers, patient groups, advisory board members and members of committees involved in regulatory and policy development processes.

## Value for Money Reform

In 2013 the *Grattan Institute* wrote a paper *Australia's Bad Drug Deal: High Pharmaceutical Prices* critical of the Pharmaceutical Benefits Scheme (PBS). It stated there is no upper limit on expenditure on PBS drugs and 'decisions on drug pricing are opaque' and 'unconstrained by a budget'. In contrast in New Zealand 'politicians decide how much is spent on drugs in total, then independent experts negotiate prices'. The Institute recommended that the Australian Government replicate New Zealand's approach and establish a single agency responsible for the administration of the PBS. They proposed this agency should operate within a fixed budget set by government and decide which medications are subsidised. The same agency should also be responsible for negotiating with pharmaceutical manufacturers the maximum price and the quantum of the PBS subsidy per script. The *Grattan Institute* estimated the net benefit of the reforms they proposed were at least \$1.3 billion per annum (approximately \$56 per Australian) but possibly much more.

Aggressive negotiation has worked in the past. In 1993 government per-capita spending on prescription drugs in Australia (A\$107) and New Zealand (A\$114) was very similar. Before this 'Australia had used a relatively aggressive price negotiation program and a more systematically applied evidence based coverage policy'. However, from 1993 to 2006 total national pharmaceutical subsidy costs more than



tripled (increasing 212%) in Australia compared to remaining virtually constant in New Zealand (growing just 11%). While in 2006 there were marginally fewer brands of drugs available with public subsidy in New Zealand there were no significant differences in subsidised access 'within classes' and no evidence of poorer patient outcomes.<sup>4</sup> In summary New Zealand taxpayers get a much better deal; equivalent service at a much lower price.

There has been some limited recognition of the problem in recent months. In October 2014 there will be a very modest fall in the cost to taxpayers of PBS subsidised drugs. However, what is clear is that even after this fall in price, Australians will continue to pay way too much in taxes and at the pharmacy for prescription medications.<sup>5</sup>

### The need for political leadership

Over the last quarter century successive Australian Governments have molycoddled the industry in the mistaken belief that the pharmaceutical industry would become 'an icon of new economy manufacturing'. Even the pharmaceutical industry's peak body, *Medicines Australia* acknowledge that only a small number of pharmaceutical companies manufacture active ingredients, the remainder either manufacture only from the 'formulation stage through to packaging stage or undertake the fill/finish stage'.<sup>6</sup> The truth is we provide too much in taxpayer funded price support to the pharmaceutical industry and require too little in return.

This has not happened by accident. The lobbying and public relations skills of the pharmaceutical industry are exceptional. Negotiating a better drug deal, and establishing rigorous and transparent processes for ensuring the safety and efficacy of medications will require political courage. Without such leadership Australians will continue to pay too much, be denied fully informed consent, and be exposed to unnecessary risks.

### References

1. Duckett, S.J., P. Breadon et al (2013), *Australia's bad drug deal: high pharmaceutical prices*, Grattan Institute, Melbourne, p.2. Available at [http://grattan.edu.au/static/files/assets/5a6efeca/Australias\\_Bad\\_Drug\\_Deal\\_FINAL.pdf](http://grattan.edu.au/static/files/assets/5a6efeca/Australias_Bad_Drug_Deal_FINAL.pdf) (accessed 25 June 2013).
2. Joseph S. Ross et al, 'Guest Authorship and Ghostwriting in Publications Related to Rofecoxib: A Case Study of Industry Documents from Rofecoxib Litigation', *Journal of American Medical Association*, 299: 15 (2008).
3. Sophie Scott and Alison Branley, 'Makers of blood-thinning drug Pradaxa "put marketing ahead of safety"', *British Medical Journal finds*, *ABC News*, 4 August 2014. Available at [http://www.abc.net.au/news/2014-08-04/study-finds-information-on-anti-clotting-drug-pradaxa-withheld/5642436?WT.mc\\_id=Innovation\\_News%7CMakersOfBloodThinningDrugPradaxaPutMarketingAheadOfSafety.BritishMedicalJournalFinds\\_FBP%7Cabc](http://www.abc.net.au/news/2014-08-04/study-finds-information-on-anti-clotting-drug-pradaxa-withheld/5642436?WT.mc_id=Innovation_News%7CMakersOfBloodThinningDrugPradaxaPutMarketingAheadOfSafety.BritishMedicalJournalFinds_FBP%7Cabc)
4. Morgan S. and Boothe K 'Prescription drug subsidies in Australia and New Zealand', *Australian Prescriber* Vol 3, Number 1. February 2010. Available at [http://www.australianprescriber.com/magazine/33/1/2/4#sthash\\_ahIldOh3.dpuf](http://www.australianprescriber.com/magazine/33/1/2/4#sthash_ahIldOh3.dpuf)
5. Stephen Duckett and Peter Breadon, *Supplementary submission* to Senate Standing Committee on Community Affairs, National Health Amendment (Pharmaceutical Benefits) Bill 2014 Inquiry into the 'Supplementary submission
6. *The Australian Pharmaceuticals Industry, Winds of Change: Report of the 2009 Medicines Australia Member Economic Survey*, Medicines Australia, ACT, 2009: p16. Available at <http://medicinesaustralia.com.au/files/2011/03/20100603-pub-MedicinesAustralia-winds-of-Change.pdf>

# If only I had known...

## Advocacy Team | Health Consumers' Council

Sometimes an individual advocacy case can highlight an issue that is experienced by many people who encounter the health system. The draft pamphlet below arose from one such example.

A Sudden and Urgent visit to a hospital of a family member or friend can catch us unprepared.

Here are some Handy Hints...

..... suggestions from people who have been there

- Don't be shy about taking notes, jotting down doctors' or nurses' names, using your Notes on your phone or iPad or in another way. Stress can make it harder to remember details.
- If your family member or friend wants you there, insist on being able to stay with them.
- If you have questions, ask them at the time - you may not get the chance later.
- Stand your ground if there is something that doesn't feel right - you can always explain or apologise later.
- Try to be there at critical times, like when Consent is being given for treatment or results are being delivered, or at Discharge.
- Call in other family or friends to be on Roster (so that there is always someone present) until the crisis settles.

**Members are invited to comment on this and add any ideas of their own, based upon their experiences. Any member with a particular interest is welcome to join a small editing team to finalise this pamphlet, when all comments have been received. Comments will close on the 28th November 2014. The pamphlet will be added to the website as a community resource when finalised.**

# A very special invitation...

Louise Ford Consumer Participation Coordinator | Health Consumers' Council



Left to right: Lola, Louise, Bayo, Ranti, Olumide, Kemi, Steve & Tope

Earlier this year I was thrilled, honoured and overwhelmed to receive an invitation to speak at a conference titled 'The African Woman Summit'. This was certainly a special moment in my life. For those of you who are unaware, I have worked closely with people in various African communities (in WA) for about 25 years in both paid and unpaid capacities.

My own life has been enhanced considerably by this experience and I have learnt so much about a variety of things including family, resilience, celebrating life and, of course, peoples' experience of health care in WA. It has been an honour, a privilege and a joy and I intend to continue my association with the African community for a long time to come. I should add that my association has not only been about 'work', it has also been social and I am now 'Aunti' to many.

As result of my interaction I received an invitation to present at the Summit which was to be held at the United Nations Headquarters in New York. The focus of the Summit was the empowerment of the 'African girl-child'. Here my dilemma began, I could not present about empowering girls in Africa, I am not African, I am not in Africa and Africa itself is a huge continent with '54 sovereign states, 9 territories and 2 de facto independent states'. (Source: <http://worldpopulationreview.com/continents/africa-population/>) Within Africa there are sophisticated cities and people – who am I to talk about how to empower African girls? How to not sound patronising or, even worse, like a colonial? Discussing my concerns with the event organiser, Mrs Kemi Otegbade, helped to allay them and I eventually determined an area I felt comfortable presenting on.

Soon it was time to pack my bags and on the 20<sup>th</sup> July I left Perth for New York. Two days after arriving I was taken to meet the Nigerian Consul General, the Honourable Habib Baba Habu, OON, at the Nigerian Embassy in New York. He gave the impression of a gentle man, very warm, welcoming and gracious. Whilst this may sound rather 'stuffy' I can assure you it was not...I was accompanied by some vivacious Nigerian women and we had a great time while waiting to see the Consul General and for the remainder of the day.

After final preparations the day of the Summit arrived – the 24<sup>th</sup> July. Several of us stayed in the same hotel and were collected by a driver from the Embassy and taken to the UN Headquarters. Once there we waited for the remainder of the 'gang' before going through security and then on into the main building.

Interestingly I wasn't nervous and presented my paper with no major qualms. My topic was titled 'Young women and girls in the African Diaspora – specifically those who come to Australia as refugees'. This was an area I felt comfortable commenting on due to my work and community engagement background.

Content included Australia's geographic and cultural distance from Africa, the lack of ongoing historical contact with African people in Australia and the impact and ongoing effects of the White Australia Policy. Other areas raised were, for example, individualism versus collectivism, gender equity, Australian law and the fact that Australia is a secular society, western feminist perspectives, and collective and individual trauma as experienced by people who arrive as refugees.

This was followed by suggested strategies to empower girls e.g. education, including educating families and communities about life in Australia, engaging girls (and families) in sporting activities, providing education and information about the role of police and the rule of law in Australian society along with the notion of 'rights' and ensuring that in the process of empowering women/girls we are also empowering men with knowledge and options. I am pleased to say the presentation was met with interest and I received positive feedback throughout the day.



A young woman who had arrived in the US as a refugee from Sudan spoke of her appreciation of the services and support that had been made available to her.



Awards were presented to outstanding women by the Nigerian Consul General

The remainder of my time in New York was spent catching up with friends, attending a Yoruba Naming Ceremony, some sight-seeing and generally recharging my batteries. It will remain an honour and a privilege to have been invited to present; I have made new friends and connections and will remember the experience for the rest of my life. Hopefully there will be more such experiences along the way. ■

# Safety in schools

Jessica Richards | Kidsafe WA

Schools are the second most frequent location for childhood injuries to occur after the home, accounting for just under 12% of all injury presentations to the Princess Margaret Hospital Emergency Department. During the year there were 2,291 individual presentations to PMH by children injured at school, with the latest statistics showing that 61% of recorded school based injury presentations occur in primary school aged children between 5 and 12 years of age.

Males account for just under two thirds of school based injuries. The high number of males presenting with school based injuries is consistent with a common trend for males to be over-represented across total injury data. This over-representation is often associated to a general tendency for males to participate in more risk taking behaviours.

Commonly school based injuries are caused by falls and blunt force that usually occur as part of sport or playground activities. Australian Rules Football, soccer and basketball are some of the sports associated with injuries at school along with improper use of playground equipment.

Bumps and grazes are a normal part of childhood, however there are some injuries that have severe and lasting effects. To help prevent unintentional injuries at school follow these tips:

- Make sure adequate supervision is provided while children are in the classroom or at play
- Ensure playground equipment is appropriate for the intended age group and that it is not used inappropriately e.g. sitting on top of monkey bars
- Avoid over-crowding in play areas
- Promote the use of safety equipment for sporting activities e.g. mouthguards, helmets and shin pads
- Check that your school has suitable safety structures and procedures in place.

Kidsafe WA supported by the Princess Margaret Hospital Foundation coordinate the Safety in Schools Program to promote safety and injury prevention throughout primary schools in Western Australia. Currently primary school students can enter the Get Creative about Safety Competition, including the Spot the Hazards Colouring In, Design a Comic Strip and Online Treasure Hunt. Entries close Friday the 7<sup>th</sup> of November 2014.

For more information on the Safety in Schools Program and the Get Creative about Safety Competition visit: <http://www.kidsafewa.com.au/safetyinschoolsweek>.





# Absurdity and evidence: As told to national workshop

**Mark Metherell** Communications Director | Consumer Health Forum (CHF)

For all its strength, absurdities do haunt Australia's health "system". It was this subject which made for a cracking start to Consumer Health Forum's (CHF) national workshop this week. Veteran News Ltd health editor, **Sue Dunlevy**, kick-started the workshop convened to discuss the consumers' role in health at a time of change.

The two-day meeting in Melbourne heard a flood of ideas to boost the consumers' role and improve health care. It made for a refreshing contrast to the Medicare co-payment debate which is clouding the future of health care.

Dunlevy opened her speech by comparing the outcomes of two elderly relatives both with health insurance and both in need of hospital care for serious illness. One chose a public hospital where she was admitted and treated promptly at no direct cost. The other went to a private hospital, and having paid insurance premiums all her life, found herself shelling out tens of thousands of dollars for services not fully covered by either Medicare or her health fund.

Dunlevy went on to make the point that our hybrid system swings from public to private emphasis with each change of government. The problem with ideology, she said, was that what worked in general rarely ever works in the particular, especially with health care.

So how does an organisation like CHF cope with "yoyo policy" changes? Dunlevy's response: Produce the evidence that highlights the flaws. Evidence presented by speakers to the 80-odd who attended the workshop left many with a refreshed sense of the strength and potential of the consumer voice in our health system.

Western Sydney's primary health champion, Dr Di O'Halloran, urged CHF to press for the importance of local consumer and community involvement at all levels of the new primary health network structure. Noni Bourke from Peninsula Health and Laura Elkin, Aboriginal Advocacy Manager from Perth, gave insights into their experience with generating consumer awareness.

Public Health Association's CEO, Michael Moore, said the axing of preventive health and hospital growth funding and the impending demise of Medicare Locals had left a gap in program delivery and highlighted the need for advocacy to improve understanding of the impact of the cuts, challenge "reactionary thinking" and recognise the social determinants of health.

There was evidence of a new dynamic of consumer influence in health care. We heard from CHF's Donna Stephenson about principles of consumer-centered care, and from Dr Jenny May and Jan Donovan about the CHF-developed Real People Real Data tool to bring consumer evidence to health decisions. The National Health Performance Authority's Tricia Linehan and Adam Cresswell demonstrated how to use the swathe of data on local health



Pictured on the podium is HCC Aboriginal Advocacy Manager Laura Elkin

outcomes and Professor Michael Greco spoke on the consumer-empowering Patient Opinion project.

Day Two opened with the heavy hitters talking on the general theme “Seven ideas to replace the \$7 co-payment”. Professor Stephen Duckett’s seven tips included: Don’t panic and cut waste before cutting access or quality. Health service waste guru Associate Professor Adam Elshaug, identified high-cost but often inappropriate procedures. Consumer health analyst, Jennifer Doggett, took a witty look at the “Seven Wonders of Health Funding”, including “the Colossal Health Funding Myth”, showing how health expenditure has remained stable in Australia. Professor Andrew Podger said he did not necessarily oppose co-payments but the current un-offset proposal was the wrong way to go.

Using social media to support consumer representation was another session which showed many of us just how connected we can be in boosting the ideas and influence of consumers.

Pioneering *Croakey* blog founder, Melissa Sweet, along with switched on social media exponents Melissa Cadzow, Delia Scales and Justin Coleman, “GP transparency campaigner”, took the conference to new horizons.

The last session featured a top grade consumer health line-up: Alison Marcus, Dr Christine Walker, Debra Kay and Deb Smith, all of whom spoke with authority on the theme of managing motivation through times of change.

One thing we know in consumer health is there will always be change: the trick is to learn how to make the best of it, as Christine Walker advised.

*CHF is the National Organisation representing the interests of Australian healthcare consumers. They work to achieve safe, good quality, timely healthcare for all Australians, supported by the best health information and systems the country can afford. This article was first published on the Consumer Health Forum of Australia, Our Health Blog on the 22nd of August 2014.*

# Real People; Real Data

## Lucy Carter Operations Manager | Health Consumers' Council

Earlier this year Consumer Health Form (CHF) approached the HCC and asked us to participate in the *Real People, Real Data* project trialling a new guide for Health Organisations to map patient journeys. The HCC project team was headed by Aboriginal Advocacy Manager, Laura Elkin with support from Ann Jones, Carly Parry, Eileen McRory and myself.

The project involved approaching 5 individuals to ask them to share their patient journey. As you can imagine, this process can be difficult for some, who are being asked to relive an experience that they may want to forget. To help the participant feel safe divulging their story, they remain anonymous, with any names removed to protect their privacy.

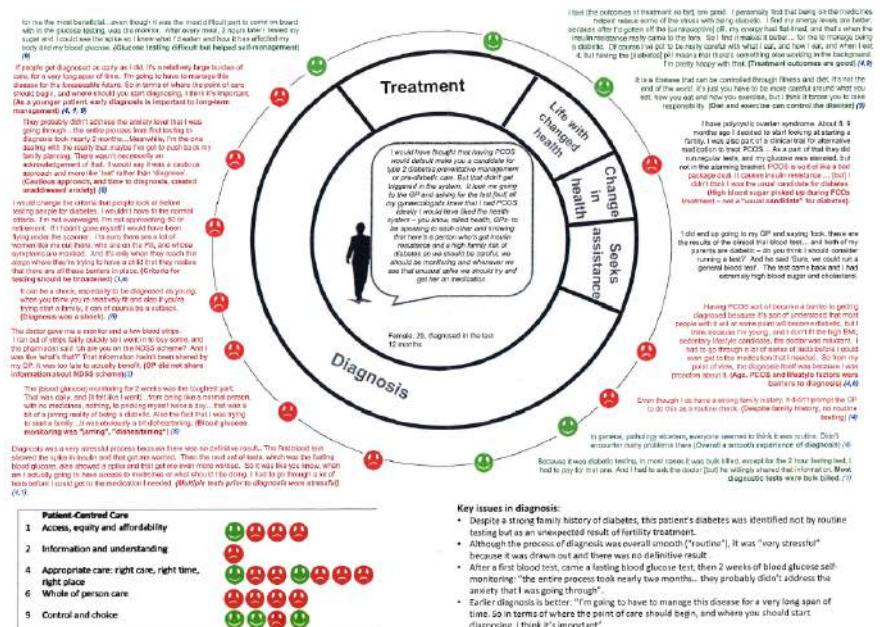
The process began by interviewing the individuals about their health and healthcare. A transcript of the interview was typed up. Then the highs and lows of their experience were highlighted and put into a spreadsheet. This was then sent to CHF who will put each participants journey into a wheel diagram, breaking down the different experiences that the patient had on their journey.

The guide has been developed as a tool to gather information regarding health, illness and the health system. It is aimed at providing health services with an easy-to-use and cost-effective method of identifying gaps in the health system and to help inform health decision-making. Robust data about consumer experience and health outcomes are critical if we are to encourage patient-centred care, ensure consistent high quality in health services, respond to local and national health priorities and improve the health of Australians.

In the Health Consumers' Council's individual advocacy work, the advocates listen to patient journeys every day and the problems they have encountered. If this tool is used to identify the gaps in the health system then hopefully the HCC will not be coming across so many consumers with the same problems time and time again.

There will always be problems with our health system, because let's face it nothing can work perfectly one hundred percent of the time, but if we can work together so that the problems are fewer and far between, then we have gone some way to making our health system the best that it can be. The guide is expected to be available in November. For more information on the *Real People, Real Data* project go to:

[www.chf.org.au/real-people-real-data-project.php](http://www.chf.org.au/real-people-real-data-project.php)



# Health Consumers Council AGM 2014

Lucy Carter Operations Manager | Health Consumers' Council



Fiona Stanley presenting her speech at the HCC AGM

The AGM was well attended with guest speaker Professor Fiona Stanley attracting an enthusiastic audience. Professor Stanley had us entranced with the obvious passion she has for her job, as well as her support of Aboriginal medical professionals and for health consumers in the field of paediatrics.

Professor Stanley also spoke of her personal situation as advocate for her husband who is suffering from cancer. She spoke of the struggles that she has come up against even as a medical professional and sympathised with other health consumers who don't have that support. Through advocating for her husband she has become aware of a lack of knowledge among health professionals of the latest developments in adult cancer research.

Fiona mentioned that it has been a little odd having a hospital named after her and that she had suggested other names, but they had all been turned down.

She would like to see the Fiona Stanley Hospital using evidence based medicine and randomised controlled trials to research health outcomes. Professor Stanley used an example of a trial that was conducted in the US offering free parking for mothers with children in intensive care. Because mothers could afford to spend more time at the hospital it resulted in less fatalities and they also had a shorter length of stay for children in intensive care. Just an example of how something that seems small, can make a huge difference.

All in all it was a successful evening and I would like to see an even larger turn out for the Consumer Excellence Awards which promises to be a wonderful event held in the beautiful Palms Community Centre in Subiaco. I hope to see you there!



# Diversity Dialogues: Mental Health

**Louise Ford** Consumer Participation Coordinator | Health Consumers' Council

In partnership with CommunityWest, the Health Consumers Council held a Diversity Dialogues forum at the Mirrabooka Multicultural Centre, Mirrabooka. The Panel consisted of Pearl Proud, Dr Bernadette Wright and Safi Mutambala. The focus of the forum was on mental health, specifically those working with people from diverse cultural backgrounds, including those who have arrived in Australia as refugees.

The event was attended by a large group of people from a wide variety of organisations including the Red Cross, Alzheimer's Australia WA, Advocare, the Dept. of Human Services, the Dept. of Health, the AMEP (counsellors), Relationships Australia, the Independent Living Centre (ILS) and Panorama Health Network.



From left to right: Pearl Proud, Dr Bernadette Wright, Safi Mutambala

Often those that have arrived in Australia as refugees have suffered from some form of trauma. In the context of this summary it seems appropriate to use a definition of Post Traumatic Stress Disorder (PTSD): “The American Psychiatric Association's current definition of PTSD, introduced in 1994, states that a person must have experienced or witnessed an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others, and which involved fear, helplessness, or horror.” (Source: <http://www.psychologytoday.com/blog/what-doesnt-kill-us/201201/what-is-trauma>).

The panel members provided perspectives on their experience working with people from diverse backgrounds in mental health. Each stressed of the importance of trust to work effectively with clients. This has implications regarding service delivery as it adds additional time to each meeting which needs to



be accommodated. It is also important to allocate extra time when working with interpreters.

Several comments/recommendations came out of the forum, these were:

- The cost of interpreters is not covered in private practice (psychology), there is no rebate which means the cost is passed on to the client, many cannot afford that cost so do not access services
- There is a lack of access to psychologists for aged people
- GPs continue to under access interpreter services i.e. TIS, although they can access that service free of charge (it is funded federally)
- Education regarding mental health, including psychology, needs to be provided to communities, this would also assist with building their confidence about accessing services
- There is a need for continual monitoring/education of interpreters around confidentiality
- There is a need for more bi-lingual/bi-cultural workers
- There is a need for more forums that encourage learning, engagement and networking
- A request was made for an email list of contacts with a brief of services provided



The Health Consumers' Council has noted these comments and recommendations and will action them accordingly. Evaluations collected on the day were positive and contained many suggestions and requests for future forums.

The HCC and CommunityWest thank those who participated and made the August Diversity Dialogues so enjoyable and engaging. Thanks goes to Fadzi Whande, Diversity Consultant with CommunityWest, for her enthusiasm for and commitment to the forum and also to Michelle Atkinson-de Garis for her much appreciated assistance in setting up and taking registrations on the day. Huge thanks also go to the Panel members; Pearl Proud, Dr Bernadette Wright and Safi Mutambala, without you the forum could not have happened. ■



# What do the arts have to do with health and wellbeing?

**Deborah Pearson** Group Coordinator Arts and Health Group Services WA | St John of God

The benefits the arts have on healing and how the arts can be better integrated into our health services in Western Australia was addressed at a recent seminar in Perth, jointly hosted by the Chamber of Arts and Culture WA and the State's largest private health care provider, St John of God Health Care.



“Love and Compassion” by Susan Sutton commissioned by St John of God Geelong Hospital for reception area of newly redeveloped hospital 2014.

In his opening address to the *Undiscovered Opportunities: Arts in the Healing Environment Seminar*, St John of God Health Care Group Chief Executive Officer, Dr Michael Stanford said research had shown that the arts can positively influence patient care and the environment in which health care is delivered. “The arts, in all its forms, can induce positive physiological and psychological changes in patient outcomes, reduce drug consumption and shorten the time a patient spends in hospital.”

“For those working in the health environment, incorporating the arts into our hospitals and health facilities can lead to better job satisfaction, improve relationships with patients and develop health practitioners’ empathy across gender and cultural diversity.

The seminar show-cased successful arts programs in health care settings around Australia including the 20 year old Arts in Health Program at Flinders Medical Centre in Adelaide; the Royal Children’s Hospital in Melbourne and the Hush Foundation which engages composers and musicians with children and their families. Local hospital examples include Royal Perth and Sir Charles Gairdner Hospitals’ visual arts program; innovative architecture and landscape design for the new Fiona Stanley and St John of God Midland Hospitals and the QEII Medical Centre; and the partnership between Princess Margaret Children’s Hospital and the West Australian Symphony Orchestra.

Dr Stanford highlighted the need to do more of what has already been discovered to promote healing and wellbeing. “It is common within the health care system that good practice is known and agreed but takes many years to diffuse into routine practice across the sector,” Dr Stanford said.



WA Artist Phillip Cook's work 'Herne Hill' is a regular stopping point for patients and staff at St John of God Murdoch Hospital

“The arts can also play a much greater part in enhancing holistic health, healing and wellbeing for each individual in our care as well as in the broader community.”

The Australia Council reported in May this year in its report *Arts in Daily Life* that the majority of Australians believe that participation in the arts makes for a richer and more meaningful life and that the arts have an impact on the ability to deal with stress, anxiety and depression and provide a personal sense of well-being and happiness.

As part of its commitment to arts and health, St John of God Health Care is working with staff and health consumers in its hospitals to identify opportunities to further incorporate the arts to make their hospital stay richer and more meaningful.

St John of God Murdoch Hospital has a gallery with regularly changing art exhibitions and an art TV channel so that patients can visit the collection virtually and hear artists talk about their work. Musicians play in public waiting areas, within wards and with patients on request at St John of God Bendigo and Geelong Hospitals. Many St John of God hospitals have artists working with patients in creative arts activities. Many invite students and local community groups to perform throughout the year.

The Health Consumers Council would like to publish further examples of how the arts are being used in hospitals and other health care settings and the impact they have on health consumers and staff. If you would like to submit an article please contact the Health Consumers' Council via [info@hconc.org.au](mailto:info@hconc.org.au) or call 9221 3422 for more information. ■



Hospital Community Choir St John of God Bendigo Hospital



# New elder abuse helpline for West Australians'

Seniors and Volunteering Minister Tony Simpson has officially launched the new WA Elder Abuse Helpline. A landmark study released by the University of Western Australia estimated 1 in 20 older people will experience abuse. The helpline is the start of a movement to dramatically reduce these figures.

The helpline is the first of its kind in Western Australia and will offer older people at risk of, or experiencing abuse an easy, independent and professional avenue to access support and assistance. It is a free state-wide service, funded by the Department of Health WA and the Department for Local Government and Communities, and will be operated by the leading elder abuse prevention agency, Advocare.

'It's great to see the government's commitment to preventing elder abuse which has become one of the fastest growing social issues affecting older people across Australia' said CEO of Advocare, Greg Mahney. 'No-one should be mistreated, abused or neglected and I urge people to call the service for support and information' he added.

Anyone can call the helpline to report cases of abuse or to find out more information about the service. The helpline can be accessed by calling 1300 724 679, 8.30am – 4.30pm Monday to Friday, and will be staffed by experienced professionals.

Downloadable posters and resources about the helpline are available on the Department of Local Government and Communities website <http://www.communities.wa.gov.au/communities-in-focus/seniors/Elder-abuse/Pages/default.aspx>



**Elder Abuse Helpline WA**  
**1300 724 679**

**Elder Abuse. Be Aware.  
Help is Out There.**

Free, confidential support is available for older people experiencing abuse from family or friends.

Call the leading elder abuse agency in WA for more information.

Monday-Friday  
8.30am-4.30pm

→ [www.advocare.org.au](http://www.advocare.org.au)

**Advocare**  
incorporated

# HCC Consumer Excellence Awards

The HCC invites members to attend the HCC Consumer Excellence Awards. Along with the new awards we also have a new venue, the Palms Community Hall in Subiaco. As this issue went to print we were still waiting for confirmation from the awards presenter. The person will be announced in due course.

- Date** Friday 5th December 2013  
**Time** 9:30am - 12:00pm  
**Location** The Palms Community Hall, corner of Nicholson Road and Rokeby Road, Subiaco.  
**Parking** Limited free parking is available at the Hall, there is also street parking available.  
**RSVP** As this is a catered event, **RSVP is essential by no later than November 28th 2014.**  
Email [info@hconc.org.au](mailto:info@hconc.org.au) or call 9221 3422.

We would love to see you there!



HEALTH CONSUMERS'  
COUNCIL  
YOUR VOICE ON HEALTH

## Seeking nominations for the HCC Consumer Excellence Awards

The Board is seeking nominations from members and the public for our exciting new awards to recognise the unsung heroes behind the scenes in WA Health.

1. Rosemary Caithness Award for personal service to health consumers
2. Lifetime Achievement Award
3. Team Project Award
4. Consumer Leadership Award
5. Innovation Award
6. Health Partnership Award
7. Health Professional Award
8. Regional Services Award
9. HCC Member Organisation of the Year Award
10. Outstanding Young Consumer of the Year Award

Please find your nomination form enclosed. Scan and send the completed form to [info@hconc.org.au](mailto:info@hconc.org.au) or post to GPO Box C134, PERTH WA 6839. Nominations close Monday 18th November.

If you require more than one form, contact the Health Consumers' Council on (08) 9221 3422 or email [info@hconc.org.au](mailto:info@hconc.org.au)





**HEALTH CONSUMERS'  
COUNCIL**  
YOUR VOICE ON HEALTH

**Health Consumers' Council**

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